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Invitation to Grief in the Family Context

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Abstract

Grief is a family affair, yet is commonly viewed as an individual phenomenon. As an international, interdisciplinary team, we explore grief within a family context across theoretical, research, practice, and educational domains. Families are complex and working with this complexity is challenging but necessary for a holistic view of grief. We therefore encourage an increased focus on theorizing, researching, practicing, and educating using innovative approaches to address the complexities of grief within the context of families. Learnings from within each domain will affirm and enhance the development of family level thinking and approaches.

Invitation to Grief in the Family Context

One of the most important settings within which grief may be experienced is the family. Thus, grief is a family affair. However, this outwardly accepted consensus must be made explicit due to the individual focus that dominates thanatological theory, research, practice, and education (Breen & O'Connor, 2007; Murray, Toth, & Clinkinbeard, 2005; N. Thompson, 2012, N. Thompson et al., 2016). Although a seemingly simple task, identifying what we mean by "family" can be surprisingly challenging, particularly when attempting to account for cultural and societal variations (Gubrium & Holstein, 1990). In an effort to be inclusive, we define a family as a web of relationships (Klass, Silverman, & Nickman, 1996) that is individually experienced; may have legal, biological, and/or relational bases; and exists within social, temporal, and cultural contexts. A family is fluid, constantly evolving and dynamic in that it may be self-defined by each of its individuals without necessarily requiring consensus. Finally, it is not defined solely by legal ties, genes, or relational bonds. This definition is important because families are commonly assumed to be static and tend to be considered within medico-legal frameworks (Miller, 2014), which overlooks for what, and for whom, the family has meaning.

Death occurs at different developmental stages of family members while also occurring at different phases of a family's development (Walsh & McGoldrick, 2013); it imposes new demands and transitions for grieving family members. This is the case whether the death is sudden and unexpected or anticipated following an illness. The transitions may begin prior to a family member's death when a life-threatening diagnosis is given to a family member. Families are complex in that they have pre-existing stressors and strains, hardships, demands, and histories that may include secrets, dysfunction, and abuse (Fisher, 2004; Macpherson, 2009). Families also vary in their structure and organization (e.g., birth order and spacing, gender, blended families, hierarchies, alliances), including the processes by

which power and authority are ascribed (e.g., roles, rules, and responsibilities), and in their experiences of previous losses, communication and coping styles, and adaptive responses (Kissane et al., 1996; Kissane et al., 2016; Nadeau, 1998; Walsh, 2003). Furthermore, these factors are interrelated, often giving rise to dynamic processes rather than being distinct concepts or standalone variables.

Our collective experience as clinicians and researchers from various disciplines (nursing, social work, psychology, family studies) working in a wide variety of settings (private practice, acute hospitals, intensive care, specialist palliative care, universities, support groups, social networks) and countries (US, Scotland, Brazil, Ireland, Australia) led us to discuss extensively and agree that families do not grieve; instead, individuals within families grieve, and they do so in the *context* of family (Gilbert, 1996). However, grief theory and practice often personifies family grief as a monolithic entity which misses the opportunity to critique such reification and bypasses the opportunity to explore the interactive, developmental nature of grief in the family. The purpose of this paper is to challenge us to view grief through a family lens within theory, research, practice, and education.

Theory

Systems theories (e.g., Bowen, 1978; Bronfenbrenner, 1979; Hess & Handel, 1959; Walsh, 2006) provide a useful lens through which we can consider grief within the family context. Some of these theories and frameworks, combined with grief theory and practice, have informed the study of and/or intervention for loss in the family. They include family systems theory (Walsh & McGoldrick, 1991, 2004), family development theory (Shapiro, 1994), and attachment theory (Bowlby, 1980). Systems theories have their nuances and differences but share an emphasis on complexity, context, and inter-subjectivity whereby family members co-create collectively agreed-upon truths and stories (Nadeau, 1998). They

may have further utility if combined into integrative models (Murray et al., 2005). An example can be found in the conceptualization of Loukas, Twotchell, Piejak, Fitzgerald, and Zucker (1998); identifying the family as "a unity of interacting personalities" (Burgess, 1926/1972, pp. 6-7), they proposed the combination of family systems, family development, and symbolic interaction to examine families and their members, individually and in interaction with each other, as well as others outside the family. Such a framework might prove useful when considering the family from multiple levels, particularly with regard to how families as a system adjust to the loss of a member while individual family members simultaneously cope with an altered family and what that alteration means to each of them.

The language, norms, and capacities within a family can provide containment which may ultimately enhance individual development and meaning-making in responding to a member's death. In acknowledging a family as a system within which grief occurs, we need to also recognize that families exists within other, related systems (e.g., a health system, a death system) and these systems may also interact with, promote, and constrain grief. Thus, the grief experiences of individuals and family members are in many ways largely shaped by social processes, structures, and expectations (N. Thompson, 2012). For example, in facing an anticipated death, both patients and family members may feel pressured to perform the heroic death of the stoic, rendering disapproval of the display of emotion from individuals in the family system (Seale, 1995). And family members who expect, having experienced the same loss that they will experience the same grief, may find themselves disoriented and isolated within the family, perhaps even questioning if they are truly a member of the family (Gilbert, 1996).

There are several grief theories that are amenable to the family lens. For instance, meaning-making, which typically refers to a largely individualized process of comprehending the loss, find personal significance, and reconstructing identity (Neimeyer, 2016; Park, 2010),

has been explored within the family system (Davis, Harasymchuk, & Wohl, 2012; Gilbert, 1996; Nadeau, 1998). The Dual-Process Model of grief has also recently been extended to take into account family processes (Stroebe & Schut, 2015). These theories (and others) provide a foundation for understanding grief within the context of the family. Further work needs to be undertaken to integrate theories of family with theories of grief to account for the complexities and layers within families. Indeed, Stroebe and Schut (2015) lamented the lack of integration between individual and family perspectives on grief.

Research

An examination of the family as the unit of analysis requires sophisticated methods of data collection and analyses that include multiple family members precisely because complete agreement about meanings attached to a death within a family is highly unlikely. The lines between individual and shared meaning-making are blurred, fluid, and demonstrate an ongoing interactive process (Nadeau, 1998) wherein multiple grief experiences co-exist for individuals and sub-systems involved (Gilbert, 1996). Due to this inherent complexity, the issue of methodology must be considered up front. While qualitative, quantitative, and mixed-method research designs can be used to study families, their application requires more than the addition of a few family-like variables. It also requires recognition that collecting data from an individual family member about the family is not the same as collecting data from multiple family members. This difference may be explained as a contrast between family-related research versus family research (Feetham, 1991); the latter has also been referred to as whole-family methodology (Handel, 1997). While one family member is studied in family-related research studies, multiple family members are studied in family research studies. Thus, for family research to occur, the family focus must be considered a priori so that it informs the development of the research question, the choice of study design, the strategies of data collection and analysis, and the presentation and dissemination of results

so that the complexity of the phenomena of interest may be captured. This is especially important given the limitations of current instruments to assess couple and family interactions pertaining to bereavement (Hooghe, De Mol, Baetens, & Zech, 2013). As Gilbert (1996) expressed, "to truly understand the nature of grief in families, it is necessary to recognize that both individual and relational factors are operating and that these must be considered simultaneously" (p. 271).

It is essential to study grief both from an individual's perspective and from within the family context. However, much of what we know about grief has been derived from data collected from one individual in the family. Commonly in family research, this family spokesperson is a woman (Saffilios-Rothschild, 1969). One example is a study by Peppers and Knapp (1980), which asked perinatally-bereaved mothers about their grief and that of their husbands. Unsurprisingly, the women's grief was richly detailed while the men's grief was stereotypic and shallow. However, because it was one of only a handful of studies that purported to represent men's grief, they were commonly cited, which reinforced the notion that men grieved for only a short time, were not very emotional when they did, and were likely not as attached to the baby as their wives. Subsequent studies that actually collected data from bereaved men provided a much deeper, more complex picture of grief they experienced and the efforts they made to protect their wives from the intensity of their emotions (Gilbert & Smart, 1992; Martin & Doka, 2000). It is worth remembering that "no member of any family is a sufficient source of information for that family" (Handel, 1997, p. 346).

There are few exemplars of methods of data collection and analysis designed specifically to capture individual and family stories and their interactions. One example is the qualitative action-project method (Marshall, Zaidman-Zait, Domene, & Young, 2012), which facilitates the collection of individual and shared stories and was recently used to explore

family meaning-making following bereavement (Bartel, 2016). It is essential that we develop more of these strategies as well as adapt existing ones to family research investigations. Several methods of data collection are likely to be useful and the choice of methods may vary depending on the study conducted. Quantitative investigations may use psychometrically-validated tools to measure concepts such as stress, anxiety, depression, family management, family functioning, and family resilience. Qualitative investigations may include data collection strategies such as observations of family interactions and interviews of families and sub-groups within families (Bousso, Misko, Mendes-Castillo, & Rossato, 2012; Wiegand, 2012; Wiegand & Petri, 2010). Additional family data can be obtained from family genograms, timelines, and family documents, photographs, images, and art (B. E. Thompson & Neimeyer, 2014). Data can be collected with family members in-person, via the telephone, and through the internet including blogs and social media. Additional data can be collected via family members' journals and diaries. In exploring these options, what is important is that the research question and the methods of data collection and analysis prioritize the family as the unit of analysis (Angelo et al., 2009; Ayres, Kavanaugh, & Knafl, 2003) by including a multi-informant and multi-level approach (Hooghe et al., 2013).

Despite the need for rigorous family research, there are many barriers to conducting such investigations. For instance, recruiting multiple individuals from the same family can be challenging because not all family members may want to participate in research on sensitive topics (Daly, 1992; Ellis, 2007), and this may be especially true when approaching the end of life (Bentley & O'Connor, 2015; Kissane et al., 1996). Retention within studies is another barrier, particularly for longitudinal data collection that could provide an understanding of the development of iterative and emergent grief processes. Such studies are relatively rare, despite providing important insights concerning causal relationships between variables such as the effect of family expression within the family on the grief outcomes of its members

(e.g., Traylor, Hayslip, Kaminski, & York, 2010). Additionally, individuals within the one family may withdraw from the study so that studies designed to be family research may at best result in family-related research that then reinforces an individual focus.

There is also the potential for gatekeeping, not just by one or more family members, but also by staff, services, and institutional review boards/ethics committees, who may desire to 'protect' family members, particularly from prospective research, over-riding the capacity of potential participants to volunteer in grief studies (Bentley & O'Connor, 2015). This problem is particularly evident when children are family members and professional anxiety prevents access for researchers to children and parents (Fearnley, 2012). Indeed, recent work suggests that it is acceptable, and perhaps therapeutic, for research participants who are asked to share their personal experiences (Coombs, Parker, & de Vries, 2016). However, family research does raise additional considerations and researchers must ensure that each family member is clear about the purpose of the study and signs an individual consent form while those family members who do not want to participate in family research should not be pressured to do so. Careful thought is required to manage and mitigate the risk of divulging private information from one family member to another (Rosenblatt, 1995). When studying important life events such as death in the family, sensitivity and care is needed throughout each step of the research process to minimize potential risks to research participants (Butler, Copnell, & Hall, 2017; Whitfield et al., 2015). As such, any family research protocol ideally would include provision for follow-up family therapy with a family therapist who is cognizant of end-of-life issues.

Additional considerations are necessary when involving children and adolescents in family research. Additional protection is needed, beyond those provided to adult participants in research, mostly due to challenges such as the need for appropriate adaptations of research procedures and settings to accommodate physical, cognitive, and emotional development, and

the complexities of parental involvement and family decision making regarding end-of-life and bereavement research (Institute of Medicine Committee on Clinical Research Involving Children, 2004). A decision about participating in a research study should be a shared decision between the child and the parents or guardians (Oulton, Gibson, Sell, Williams, Pratt, & Wray, 2016). While the adult consents, or gives what is increasingly referred to as parental permission on a child's behalf (Roth-Cline & Nelson, 2013), assent needs to be given by the child (Lambert & Glacken, 2011). Further, due to the power imbalance between researchers, children, and potentially their families, children should be clearly told that they can say "no" to participating in a research study and that they are free to withdraw from any research activity at any time (Ho, Reis, & Saxena, 2015).

In addition to these ethical considerations, it also may be difficult to convince funders of research of the need for family research and it can be difficult to describe the specificity required by funding bodies given that each family is distinct and family research is complex. Taken together, these challenges may explain why it is common for studies to be described as family research when the data are drawn only from one person in the family, although it also likely that the researchers might consider one family member to be an adequate proxy for the family. Although there is a slowly emerging body of research on grief within interpersonal and interactive contexts (Stroebe, Schut, & Finkenhauer, 2013), the development of individual and family perspectives remains in parallel (Stroebe & Schut, 2015). Thus, we need further work to develop definitions, measures, processes, practices, and protocols so that family research is understood, rigorous, ethical, and funded.

Practice

Practice in relation to grief and loss occurs within a wide range of settings—private practices, hospitals, palliative care centers, hospices, community-based services, funeral homes, long-term care facilities, cemeteries, faith-based organizations, mental health

services, and health services generally. These services need to be available to support bereaved family members—children and adults—who are bereaved due to the death of a neonate, child, adult, or elderly family member. Family bereavement care can be offered face-to-face with the family and may even be provided using telehealth and other creative technologies including Skype and even 3D virtual worlds (Lubas & De Leo, 2014). For some, bereavement care can be offered by telephone.

Two main and overlapping philosophies underpinning practice with families are the family as the unit of care and family-centered care. The philosophy of the family as the unit of care is particularly strong within palliative care (Baider, Cooper, & Kaplan De-Nour, 1996; Dahlin, 2013; Sepúlveda, Markin, Yoshida, & Ullrich, 2002). Family-centered care is defined as working with the family unit as the focus of care rather than focusing only on providing care to the patient (Johnson & Abraham, 2012). Family as the unit of care is structural in nature, in that it underscores how services are provided, how long and to whom, while family-centered care is process-oriented, underlying day-to-day considerations of direct care. The uncritical application of family as the unit of care or the center of practice means that services are offered to one family member as a proxy for the family, yet it cannot be assumed that care provided to one family member will be shared with others in the family (Breen & O'Connor, 2011). The World Health Organization (2017) recognizes palliative care an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness and that bereavement support for families should be included as part of end of life care. However, family members are often left with inadequate support as a result of lack of awareness amongst health and social care staff and appropriate access to bereavement support (House of Commons Health Committee, 2015). Indeed, the provision of family-centered care was recently described as "the most difficult challenge" (Kissane, 2017, p. 195) to the practice of palliative care.

Just as individuals respond differentially to loss, and may experience a range of grief expressions of varied intensity and duration (Aoun, Breen, Howting, Rumbold, McNamara, & Hegney, 2015; Bonanno et al., 2002; Kersting, Brahler, Glaesmer, & Wagner, 2011; Neilsen, Neergaard, Jensen, Vedsted, Bro, & Guldin, 2017), there are also differences in how family members within a family grieve. A clinical case study approach to describing a couple's communication following the death of their son/stepson helped to uncover the complexities about grief communication within families (Hooghe, Neimeyer, & Rober, 2011). Based on the findings, the authors recommended that therapists reconsider the promotion of grief expression within families, and instead focus on creating opportunities for family members to share their grief experiences outside of the family. Kissane and colleagues (Kissane et al., 1996; Kissane et al., 2016) identified different family functioning profiles. While most commonly families are well-functioning and resilient in the face of loss, other families demonstrate low functioning, uninvolved, and conflictual relational styles, leaving them vulnerable to poor outcomes following bereavement.

In circumstances where a death occurs following an acute exacerbation of chronic illnesses or after a gradual decline in health, work within the family may start prior to bereavement. This early work is not possible for families faced with the unexpected illness or injury of a family member that results in death. It is essential that we assess responses to loss, prior to the death (when possible), and intervene to help families during the dying process and after the family member's death. The Leadership Alliance for Care of Dying People (2014) promotes sensitive communication and involvement in decisions by the dying person and "those identified as important to them" (p. 4). It is the dying person then, if able, who should define who is in the family. However, family members are not typically viewed as patients and this can provide a barrier for their assessment and delivery of care, especially post-bereavement (Randall & Downie, 2006; Sealey et al., 2015). Family meetings are seen

as a way of providing support to families but the focus tends to be on the provision of information, sharing of concerns and planning of care (Hudson et al., 2008), particularly in advance of discharge from an inpatient or hospice facility, rather than bereavement care per se. Furthermore, the evidence for the effectiveness of these interventions is currently poor (Cahill, Lobb, Sanderson, & Phillips, 2017). Additionally, at least in some settings, health professionals may not be able to communicate effectively if there are constraints on their time and if the training opportunities to develop the required skills are limited (Fearnley & Boland, 2017).

Grief support can be planned and offered to family members in acute care and other settings before and after patient deaths and this may involve tailoring existing therapeutic practices to meet the needs of grieving family members. In addition, there are interventions developed specifically for working with families such as family-focused grief therapy (Kissane & Bloch, 2002), the family bereavement program (Sandler, Wolchik, Ayers, Tein, & Luecken, 2013), and family meaning-making (Nadeau, 1998). Practitioners may be very comfortable working with individuals, but not as comfortable working with families (Kissane, 2017). In addition, there has been much greater emphasis on family-centered practice in pediatrics and specialist palliative care, but this is far less evident within other specialties of medical practice. Families are complex and it may be challenging to assess the family as a unit of care and then intervene to help, especially when services are not specifically reimbursed to do so. These issues make it difficult to conduct a family assessment to determine what is important to family members, let alone provide meaningful intervention at the family level, especially when individual and family interventions may both be needed. These reasons are likely why Stroebe and Schut (2015) recently noted that, "although some family therapy programs have become well-established in recent decades [….], the prevailing paradigm is still individual care" (p. 878).

Education

University and post-university training, across a wide range of helping professions and disciplines, tends to be limited in its conceptualization of grief (Breen, 2011; Breen, Fernandez, O'Connor, & Pember, 2013; Dickinson, 2007; Johnson, Chang, & O'Brien, 2009; Lobb et al., 2010; O'Connor & Breen, 2014). Studies have shown that counselors experience significantly higher levels of discomfort and display low empathy when faced with death and dying than with other sensitive issues (Kirchberg & Neimeyer, 1991; Kirchberg, Neimeyer, & James, 1998) and nurses experience distress when caring for bereaved family members (Gallagher et al., 2015; Kojlak, Keenan, Plotkin, Giles-Fysh, & Sibbald, 1998; Wiegand & Funk, 2012). Dealing with this discomfort is important, not only in terms of the wellbeing of frontline staff, but also to optimize the quality of care provided to family members. The provision of quality grief education can reduce discomfort and protect against the development of secondary traumatic stress in the workplace (Breen, O'Connor, Hewitt, & Lobb, 2014; Granek, Mazzotta, Tozer, & Krzyzanowska, 2012).

It is therefore essential that grief within the context of the family is taught in academic undergraduate and graduate programs for psychologists, nurses, physicians, social workers, clergy, and others who are likely to interact with and support bereaved people. While many disciplines generally, and end-of-life policies specifically, promote the family as the unit of care, these are rarely translated into content that is readily taught in classrooms and in online courses or part of core practice competencies, let alone within the context of grief. However, a family emphasis is developing, albeit slowly. For instance, The American Association of Colleges of Nursing (2016) recently published Competencies and Recommendations for Educating Undergraduate Nursing Students. One of the core competencies includes assisting the patient, family, informal caregivers and professional colleagues to cope with and build

resilience for dealing with suffering, grief, loss, and bereavement associated with serious illness.

In addition to didactic education, experiential education is needed. Once students are deemed to be competent from an educational perspective, they can observe mentors as they role model best-practice with bereaved families. Simulation sessions can be taught using case-based approaches and using live sessions with actors or virtual actors; the latter teaching method has been shown to produce increases in communication skills and confidence comparable to sessions with actors or clinical placements but is less expensive (Quail, Brundage, Spitalnick, Allen, & Beilby, 2016), although these effects have not been tested specifically for grief education.

In addition to education in the academic setting, ongoing education is needed. Interdisciplinary continuing education courses need to provide ongoing education specific to grief assessment and interventions that are focused on families. However, such information is limited. For instance, CareSearch, the palliative care knowledge network in Australia, provides information on grief but not from a family perspective. The Association for Death Education and Counseling's body of knowledge matrix features family-level variables (e.g., family roles, family history, family systems, family life cycle) within four categories—dying; end-of-life decision-making; loss grief and mourning; and assessment and intervention. The End-of-Life Nursing Education Consortium (ELNEC) project is an education initiative based in the US to improve palliative care. A key component of the course is a module titled Loss, Grief, and Bereavement. This module focuses on teaching providers how to provide care to bereaved patients and families, including conducting a grief assessment and offering supportive interventions. In Scotland, the framework developed to support the learning and development needs of the health and social services workforce emphasizes the knowledge and skills needed by the workforce to collaboratively support families and carers during end-

of-life care and post-bereavement (National Health Service Education for Scotland and Scottish Social Services Council, 2017). Whilst supporting families with loss, grief, and bereavement is viewed as integral to all palliative and end-of-life care provision (Scottish Government, 2015), in-depth knowledge about how to assess and support the family as a unit remains restricted to specialist palliative care services.

These university and post-university training initiatives would be well-supported by grief education in our communities. At the community level, there is increasing focus on building the community's capacity to help others and process losses at the end-of-life (Kellehear, 2013; Sallnow & Paul, 2015) and following bereavement (Murray, 2002; Rumbold & Aoun, 2014, 2016). This holistic focus to support provision, at the level of the community, would encapsulate the family focus. Information on bereavement experiences from bereaved people themselves may be particularly instructive in order to improve bereavement care that may be professionalized or provided within natural support networks (Breen, Aoun, Rumbold, McNamara, Howting, & Mancini, 2017). In just the same way, information on bereavement experiences from individuals within the context of families would also be useful to guide bereavement care practices that account for and address the interactive, developmental nature of grief in the family.

Conclusion

In this article, we have mapped the landscape of grief within the context of the family. The individualized approach that dominates grief theory, research, practice, and education means that we might neither see nor appreciate the phenomenon of grief in its entirety. Clearly, working with the complexity afforded by families is challenging. While the family perspective of grief is building, there remains a lack of integration between individual and family perspectives yet the broader we look, the more complexity we see. The focus should not just be about individuals, but nor should it just be about families; instead, it is both the

individual and those who comprise the family that are of interest because of their often overalapping, but not completely concordant, realities.

We argue that our field has not progressed grief from the individual focus to within the lens of families because doing so is hard, but that does not mean we should not do so. While individual interventions may lead to positive individual outcomes, family interventions may lead to better outcomes for individual family members and for the family. We must be sensitive to the complexities in order to determine how to theorize, research, practice, and educate using innovative approaches to address the complexities of grief within the context of families. Grief occurs within a family and we hope that this article can go some way to urging the development of family level thinking and approaches into grief theory, research, practice, and education.

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